

MEDICARE PAYMENT ADVISORY COMMISSION

PUBLIC MEETING

Ronald Reagan Building
International Trade Center
Horizon Ballroom
1300 13th Street, N.W.
Washington, D.C.

Friday, November 16, 2001
9:01 a.m.

COMMISSIONERS PRESENT:

GLENN M. HACKBARTH, Chair
ROBERT D. REISCHAUER, Ph.D., Vice Chair
BEATRICE S. BRAUN, M.D.
SHEILA P. BURKE
ALLEN FEEZOR
FLOYD D. LOOP, M.D.
RALPH W. MULLER
ALAN R. NELSON, M.D.
JOSEPH P. NEWHOUSE, Ph.D.
JANET G. NEWPORT
CAROL RAPHAEL
ALICE ROSENBLATT
JOHN W. ROWE, M.D.
RAY A. STOWERS, D.O.
MARY K. WAKEFIELD, Ph.D.

Agenda item:

Access to Medicare's hospice benefit

Medicare beneficiaries access to hospice services:
an initial analysis

-- Chris Hogan, Direct Research, LLC

Results of interviews with experts in hospice care

-- John J. Mahoney, Summit Business Group, LLC

Indicators of access and policy options

-- Sally Kaplan, Kevin Hayes

P R O C E E D I N G S

MR. HACKBARTH: Would everyone please take their seats?

DR. KAPLAN: Good morning. In BIPA, the Congress mandated that MedPAC study beneficiaries' access to hospice. The mandate language is on the screen and in your handouts. As you can see, the Congress is particularly interested in short stays and differences in rural and urban beneficiaries' access to hospice. We contracted with Chris Hogan and with Jay Mahoney to research these issues. After they present their findings and you've had an opportunity to discuss them with them Kevin and I will return to discuss next steps with you.

DR. HAYES: First we'll have a presentation by Chris Hogan on access to hospice care in rural areas. Many of you now Chris already. He was an analyst at PPRC and later at MedPAC. He's now the president of Direct Research, LLC.

DR. HOGAN: I used to work for this organization and one of its predecessors for many years and now I'm an independent consultant. I'm an economist, and I'm going to talk about a short study that I did on your behalf on access to hospice care.

First I'm going to tell you why I'm sitting here, and how I came to be producing this report on your behalf. Then I'm going to talk about some recent trends in hospice to try and capture the growth and change in the hospice industry in the 1990s. Next I'll look at short hospice stays using about 600 hospice-using decedents from the Medicare current beneficiary survey. So it's a small sample but it's the best I could do with the available data. I'll look at urban-rural differences, geographically-based differences in hospice use and then I'll give you some conclusions.

In terms of the background, this report is really a spinoff from an AHRQ grant that was made to the then-George Washington University Center to Improve Care of the Dying, now the Rand Center to Improve Care of the Dying. We brokered a deal: that we would get access to your data, to keep costs down, and you would

get two reports. You got the last report from us last year and it was a profile of cost and use for Medicare decedents.

This year when we consulted with your staff, what you wanted most was an early look at ways to go about meeting your mandate for this BIPA report to look at hospice access. And the way I read that mandate, the mandate specifically asked you to look at urban-rural differentials, short stays, and differences in use by the diagnosis of the patient. So that's why I'm here.

Let me go on and do recent trends. Here in one slide I've tried to condense the hospice industry to a handful of numbers. Most of these numbers came from an excellent GAO report that came out in 2000 that profiled the hospice use in the Medicare program and looked specifically at the short stay issue. There's only one number on this slide that isn't from the GAO report and that's the number I came up with for nursing homes, but the rest of it is basically public use information.

The number of hospice users in the Medicare program more than doubled over this period and the use rate went from less than 9 percent of decedents to more than 20 percent or about 20 percent of decedents between '92 and '98; tremendous growth. There was a substantial diffusion of hospice out into rural areas. So that at the start of the period rural rates were a little more than half of urban rates, and by the end of the period rural rates were up to three-quarters of urban rates.

So to the extent that there was a particular rural problem with access to hospice care, I guess the good news is it's better now than it was because the rural rates are closer to the urban rates now.

The case mix changed substantially over this period. So at the start of the period 77 percent of hospice patients were cancer patients. That's the traditional base for hospice users. And by the end of the period it was trending down toward 50/50, cancer and non-cancer. That change in case mix is going to come up again in the discussion of short stays.

Going hand in hand with that change in case mix has been the phenomenal growth of hospice in nursing homes. I have little tilde signs in front of my numbers that are 15 percent early in the period, 35 percent later in the period, because I looked at a variety of sources and there's some uncertainty as to exactly what fraction of hospice users are in nursing homes. But there's no uncertainty among any of the sources I looked at that it's the fastest growing segment of the hospice industry.

You should be aware that this raised some eyebrows at the Office of Inspector General in the mid-1990s. They didn't like some of the contracting arrangements and they pointed out that as far as they could tell it was substantially cheaper for hospices to serve patients in nursing homes than to serve patients in their own homes. I think that's a finding that makes a lot of sense. Certainly the travel costs are lower. They found that

the service levels were lower for nursing home patients. So it raised some eyebrows, but there was no action on the OIG's part. They just raised some questions.

Finally, this is the key issue for the industry I think, short stays have increased dramatically. The rounding error on my chart hides it, but roughly speaking, the number of short stays has increased by almost half between 1992 and 1998. Short stays here are arbitrarily defined as stays less than a week. It's still a trivial fraction of all the days but it's, apparently, a pretty substantial cost burden for hospices because they have to go through all of the burden of enrolling the person, then all the burden of disenrolling them, so to speak.

So that's my capsule summary of the trends in the hospice industry for the 1990s.

Let me give you the broader perspective on the entire Medicare fee-for-service program. Probably the most interesting finding, it's almost a byproduct of this report, was to say, that's great. We have hospices and they're treating an increasing share of the Medicare decedents. What's happened to site of death in the fee-for-service as a whole?

To generate this table I took a relatively small sample of beneficiaries and broke them into people who died from cancer and died from other causes, and then broke their sites of death into three pieces. If you died in a hospice, I called you a hospice site of death, regardless of your actual physical location of death. And if you died outside the hospice I went and looked at the Medicare bills and found all the people who died in inpatient settings, which I defined as hospitals and skilled nursing facilities, because there's a lot of fungibility in the site of death there, and people who died elsewhere.

The interesting finding from this chart is that while hospice has grown substantially, the site of death for Medicare beneficiaries hasn't really changed very much at all. In fact it's changed only minimally. This has implications basically for every study you've ever seen of the cost savings from hospice, because hospice cost savings are based on the assumption that if you didn't have hospice there people would be dying in the hospital. These results seem to suggest that, no, to the contrary, that people who are attracted to the hospice appear to be the people who wouldn't have died in the hospital anyway.

The bottom line here is that despite the tremendous growth, for example, in the fraction of cancer cases from 37 percent to 51 percent in hospice, in fact the number, the fraction of beneficiaries, cancer decedents dying in the hospital only dropped by 4 percent. And on the non-cancer side, despite a 6 percent increase in the fraction of non-cancer decedents in hospice there's been essentially no change in the fraction of non-cancer decedents dying in the hospital.

So that's just an interesting caveat. If you're going to

make your decisions in the context of, we all know hospice saves us money because, this is an interesting caveat to the existing studies of hospice cost savings.

DR. ROWE: Chris, could I ask a question? How could the proportion -- can you reconcile or need to reconcile these data with the data that showed that the proportion of hospice patients who are cancer patients has gone down so dramatically? When you look at the non-cancer in hospice, deaths have only gone up from 4 percent to 10 percent.

DR. HOGAN: I'm not tracking the question.

DR. ROWE: Has there been an increase in the size of the non-cancer deaths population rather than just a shift in it?

DR. HOGAN: No, still it's only about one in five Medicare beneficiaries dies from cancer. So that the number of non-cancer deaths in hospice is actually quite large because the population is four times larger than the cancer decedents.

DR. ROWE: Can you break the inpatient and SNF down? Is that mostly hospital or --

DR. HOGAN: That's mostly hospital, but not hugely mostly hospital. There's enough patients dying in the SNF that you want to include that in the package I think. My take on it was that there was a lot of substitutability between the exact site of death for people who have an inpatient stay followed by a post-acute inpatient episode. So I pooled them, because I thought that that was the right thing to do. But if you had a larger sample size you could certainly break that down and get those numbers.

DR. ROWE: The reason I ask, and I'll get off this, is that with the pressure to reduce the length of stay in hospitals, one of the -- there were two pieces of ripe, low-hanging fruit. One was admit people the day of their surgery rather than the day before. The other was transfer people who were terminally ill to skilled nursing facilities rather than keep them in the hospital, which was really the wrong place for them to be in the first place.

So I would have thought that while that total number of inpatient and SNF hasn't shifted much, that there would have been a substantial change in the relative proportions of those two as length of stay was driven down. So you might just look at that.

DR. HOGAN: If I had a larger sample of people I would have done exactly that. So that's basically all I have to say about trends in the hospice industry.

Let me give you one slide on short hospice stays. This turned out to be not hard to do with the Medicare current beneficiary survey. But you have to understand that I've run a regression with 600 people in it, so all I'm going to be able to find are the largest, grossest effects that are going to pass your traditional standards of statistical significance.

I picked stays of under two weeks instead of stays of under

one week. It's qualitatively the same population whichever way you slice it. It just gave me more people to look at so my numbers were a little more stable in this small sample of beneficiaries.

When I ran a regression, the regression had a bunch of right-hand side variables in it. What I found first was, based on the beneficiaries' self-reported diagnoses, the prevalence of short stays is strongly correlated with the diagnosis. It's not cancer patients. It's not lung cancer.

So if you look here, lung cancer patients were 13 percent less likely to have a short stay, and the people who do have the short stays are the people like congestive heart failure. That's either because the date of death is so unpredictable they just by accident die soon after they enter, or it may be that people are waiting until it's very clear these people are dying before they move them to the hospice. Either way the fact is, when you run against the diagnoses, the diagnosis mix makes a big difference in the fraction of patients who have short stays.

I did a lot back of the envelope combining these two estimates, very rough estimates, with the GAO data and I came up with the following. About a third of the increase in short stays from '92 to '98 is directly attributable to change in case mix, or is attributable to change in case mix alone, because the non-cancer patients are far more likely, at least by this estimate, to have short stays.

The second thing I looked at after discussions with Kevin and Murray, they had brought up the issue of, if hospice isn't taking of these people, who is? That's why I decided to put in a flag for whether they had any home health care in the year of death. And it turns out that, yes indeed, the beneficiaries who had home health care were more likely to have a short hospice stay.

There are two possible explanations of that. One is, they have someone to take care of them so they don't have to be in a hospice till the very end. The other is there are administrative barriers to transfer of a patient from home health to hospice. I think the genesis of these administrative barriers was to prevent the home health from going out and basically recruiting on behalf of hospice. But there is sort of an abrupt transition in the care team when you move from home health to hospice. That might be a barrier.

So it's either a substitute for hospice care or a barrier to hospice care; I'm not sure which. But the fact of the matter is, it's strongly correlated with having a short stay.

Then there was a cluster of demographics that as an economist I could make no sense -- I could tell you no sensible tale for these, and every time I try and discuss them I get the sines and the coefficients wrong, so I'm simply going to state them and leave them for your discussion.

Living in the community with your spouse means you are less likely to have a short stay. Being female means you're less likely to have a short stay. And being poor means you're less likely to have a short stay. Those three are all highly commingled. Most of the beneficiaries with incomes under \$10,000 are women living alone who have been widowed. Yet I did a relatively careful analysis on Kevin's suggestion to look at all possible combinations of these and these results are true: independent of your living status or your gender, poor people are less likely to have a short stay. Independent of your income or your living status, women are less likely to have a short stay.

So I probably have mixed a sine here one way or the other, but I have a cluster of three important demographic factors and I couldn't make any sense of this, so I'll just leave those for your discussion.

Probably the most interesting thing on this table is what is not on this table, and that is an urban-rural difference. That once you account for diagnoses and demographic factors there was no urban-rural difference in short hospice stays. So that's probably almost a check-off for this report, to say that was not a particular rural issue.

Let me go ahead and look geographically now at urban-rural differences in hospice use. The first thing I did was to take some data that Jennifer Grover and Laura Dummit at the GAO very nicely provided to me, a nice tabulation of hospice users from the 100 percent hospice files. I looked at it by state, and what you find is there is no such thing as uniform urban-rural differential in hospice use. On the eastern seaboard or the northeast coast, there's no urban-rural differential to speak of. In fact in many states the rural use rate is higher than the urban use rate.

What I did was I sorted all 50 states, took the differential, and gave you the states with the largest urban-rural differential at the top of this table and the states with the smallest urban-rural differential at the bottom of this table. So you can see in Connecticut, the use rates in Connecticut are higher -- Connecticut, New York, and Maine -- are higher in rural areas than they are in urban areas. It's only when you go out to the old frontier and the upper Midwest, if you go out to the mountain states, North Dakota and some others in that general cluster, that you find that the rural rates are substantially lower than the urban rates.

But I do need to point out that if you just look at the numbers on the face of them and read down the rural column, it's not the rural rates that change. In fact the urban-rural differential is due to very high urban rates in mountain states. The rural rate in New Mexico is higher than any of the urban rates on the east coast. So the extent to which we call this a rural access problem is problematical on the basis of that.

This was beyond my level to tell you a sensible story. I looked at that and I said, this certainly varies a lot by geography and that I'm simply going to ignore this fact for the rest of the discussion and pool all urban rates and pool all rural rates and give you urban-rural differences that pool across these state-level differences.

How do rural hospice use rates compare to urban rates by the urbanicity of the rural county? The right way to understand this chart is to realize that if I had put a line on it that said urban, the line for urban would have said 100 percent, 100 percent, 100 percent. So this is the use rate relative to the urban rate for all the rural areas as defined by their urban influence code. I broke it into cancer and non-cancer decedents, and this is based on the diagnoses on the hospice claims.

What you find is that the lower rate of use in rural areas, it's substantially lower for non-cancer diagnoses than for cancer diagnoses. So the cancer use rate is much closer to the urban rate in rural areas, and that it varies pretty much strictly by the urbanicity of the county. This shouldn't be any surprise. So that the use rates for hospice are lowest in your totally rural counties, meaning counties that don't even have a town of 2,500, and it's highest in the counties that are adjacent to urban areas or that have a city of 10,000 or more.

So I thought that this chart, in a single chart you pretty much know the story here. The more remotely rural you are, the less likely you are to have access to hospice care, and non-cancer care is primarily an urban phenomenon. Cancer care for hospice has diffused to a substantial degree to rural areas.

The final piece of this was to say -- and this was once again at your staff's suggesting -- are there any places where we have evidence of no hospice availability? This is the crudest possible way you could measure hospice availability you say, there's no hospice there. So I looked at a bunch of different sources of data to try and find any availability of hospice.

What I found is, yes, indeed, the rural counties where there's no evidence of hospice cluster in a few states, Wyoming, Montana, Nevada, South Dakota, Nebraska. North Dakota would have been there too, but the hospices in North Dakota claim to serve almost all the counties in North Dakota so I took them at their word. Anyway, these states -- and it was a clear geographic clustering, and if you look at the counties, of course, half of them are counties that are remote rural counties.

Let me give you the caveats and conclusions. This analysis was a -- quick and dirty is a little pejorative, but I used small sample files. I used what was available and I got the product on the table in front of you, using the simplest possible criterion for access to hospice which is, do you have any hospice care. That's a pretty rough cut at what is basically a very complex underlying decision.

In terms of conclusions, I'll give you two slides to summarize the contents of the presentation. Yes, the use of hospice care increased substantially from 1992 to '98; users more than doubled. The case mix shifted substantially towards non-cancer cases and towards care in nursing homes. The urban-rural differential narrowed; that hospice appeared to diffuse in rural areas. But overall, this has had a minimal impact on where Medicare patients die. They still die in the hospital at about the same rate as they did before the growth of hospice.

There's been an increased use of very short stays in hospice. There was no particular urban-rural differential, but at least some of that growth can be pretty directly attributed to the change in case mix. It's the non-cancer cases that predominantly had the short stays. Maybe the rapid growth in home health through 1997 may have contributed to this, because I think that having home health was able to keep you out of the hospice longer. But of course, that whole landscape changed in '97 so these numbers are probably unhelpful for a modern discussion. And maybe the secular trend toward shorter stays may have had influence as well.

Even now the use rate is lower in rural areas than in urban areas, but as you know that's not geographically uniform. Somewhat lower for cancer cases, a lot lower for non-cancer cases, and clearly linked to the urbanicity of the area; the more urban you are, the likelier you are to have hospice available. When I've looked for counties that had no hospice at all, they were clearly geographically clustered in just a few states.

DR. ROWE: Two points, Chris. It was very interesting. I think looking at the data that you showed that wasn't really that coherent as you looked at it about the women, and whether you're living alone, et cetera, or whether you're poor, one of the findings early on in hospice was that it was very under-utilized by minority populations, particularly African-American population compared to others. I think 3 percent utilization rates or something like that. I don't know if that's held up over time.

This was in areas in which there was access, and it was felt that perhaps a different social structure, with more people at home, more multi-generation families living in the same area, et cetera, there was more support, informal social support. Therefore, there was less need for hospice. I don't know whether those data have held up. My information is a little old on this, as it is in much of clinical medicine unfortunately.

But nonetheless, that might explain what your observation about these things just don't seem to tie together. If your sample is large enough you might look at African-American and/or Hispanic. You might have to put those two together but you might be able to do that. That might answer this question.

I don't think that's a bad thing. If we find that, this shouldn't be an initiative to improve the use. People should use

whatever resources that are available. Those are the best resources. And if not, then we should supplement them with formal resources for those people who don't have the informal resources. So I don't think it would be as bad thing if utilization is lower but it might explain the data.

The second point I would make with respect to this is, I think this is very important and useful. We were asked by Congress to do a very specific rural hospice benefit, another one of these very targeted requests that somebody got Congress to ask us to do, which is fine.

But this should not be a proxy for MedPAC's interest in care of the dying, or care at the end of life. There is more to care at the end of life than hospice, or whether hospice is available in all areas. There are lots of aspects of care at the end of life, including the education of physicians and nurses and others, and utilization of other resources in the community, and home care, et cetera. So I just want to make sure from a policy point of view that from time to time we get to this issue and we shouldn't just assume we've taken of it because we've done this project on hospice.

DR. REISCHAUER: This really isn't on the focus of what Congress asked us to do, but I was wondering, Chris, if you had some information on costs. We went into the hospice movement for two very different reasons. One was that this was a more desirable or medically appropriate setting for the end of life. And secondly, that it might save Medicare a lot of money.

I was wondering if there are any data that show trends over this period, breaking the population of decedents into those with any hospice in the last year, those with no hospice but inpatient, and those with neither inpatient nor hospice care and what's been happening to those? Because I got a feeling from what you said that maybe these differences are narrowing.

DR. HOGAN: I ran a cross-section of those numbers last year so we know the picture that people dying in the hospital cost about twice as much as people who don't die in the hospital, so that's well known. Whether there were trends in those numbers, I found it -- I don't think I had enough data to say that very well, although I could go back and look.

DR. REISCHAUER: But whether they die in the hospital doesn't tell you whether they had hospice care at some point.

DR. HOGAN: No, having divided the population into any hospice, and of those with no hospice, those who died inpatient and those who died elsewhere, you'll find the people who died in the hospital cost substantially -- as expected, they would cost about twice as much; substantially more.

The only trend number I have is that in the aggregate in the Medicare program the cost in the last year of life are essentially no different from what Lubitz measured in 1979.

DR. ROWE: Twenty-two percent?

DR. HOGAN: Twenty-six and-a-half, 27. Certainly there's been no -- if you merely bucket people by the fact of death there's been no change in the fraction of Medicare spending on those people in the last 20 or 30 years. That doesn't answer your specific question about --

DR. REISCHAUER: No, it doesn't, but it would then suggest the difference between those who die in hospice or those who die in a hospital has shrunk, I think.

DR. ROWE: I think what you have to do, Bob, is you have to break the deaths in the hospital into the kind of schedule of deaths from chronic or semi-acute diseases, and the deaths of people who have acute myocardial infarction or stroke and die within the first couple days of arrival in a hospital. That would give you more information about the comparison.

DR. HOGAN: There was a suggestion to look at the time series within geographic areas and see if the areas where hospice increased its penetration most rapidly resulted in a reduction. That analysis is just waiting to be done. So there are ways to get at it. They're all sort of indirect. I give you an aggregate table. If you had 100 percent data you could do a disaggregate table.

But the issue of whether or not there's been a secular shift in the change due to the growth of hospice that's an important question, but I don't think I could do it by putting people into, by bucketing people by hospice and site of death. I think you'd have to use more indirect methods.

DR. NELSON: Chris, I'm starting from the position that hospice is a valuable service and that it provides an additional choice and an asset for Medicare patients that are eligible and want it. To what degree -- I didn't see that your data measured it directly but can you give me an idea about capacity and the degree to which the use of hospice services is being restricted because of waiting lines, or because of a lack of hospice availability, other than just as explained by geography?

DR. HOGAN: No, I couldn't even begin to -- I don't know how I'd identify a beneficiary who tried to get hospice but couldn't except via survey. No, there's nothing that --

DR. NELSON: I guess as a practitioner I had patients tell me that they were trying to get into hospice, that they had a waiting list, that when they finally made it they were really happy. I think that we're talking about the economic implications, whether or not Medicare is providing adequate incentives to payment policies for hospices to form and stay in business. It seems to me that we can't approach that question unless we have some sense about whether there's an adequate capacity, or whether we need to sweeten the pot, or whether the pot is perfectly sweet and everybody that wants hospice can get in. I guess at some point our staff needs to think about how we might get that kind of information.

MS. RAPHAEL: I was interested in several things that you highlighted in the text that you didn't refer to today. One is that the percent of hospice users who use it for four weeks or less, as I recall also went up by about 12 percent, and I thought that was interesting. I was wondering if you could comment on that.

Secondly, you also mention the fact that if you are a member of Medicare+Choice or you have a Medigap policy you're more likely to use hospice. That's in accord with my own experience, that we have a very high percentage of Medicare+Choice and Medigap policyholders in our hospice program. It really is striking compared to home health care utilization, for example.

DR. HOGAN: Comments on the two of those. The four week or less, I had nothing of interest to say there. There's been such a secular decline in lengths of stay that I thought that that would just -- putting any arbitrary boundary on a reasonable length of stay seemed like you're going to have -- because stays have been falling generally, you're going to have more people falling into that boundary. I didn't have any -- I don't think that's where the industry's interest was focused and I didn't have anything in particular to say about that.

With regard to Medicare+Choice and Medigap, I found those -- as an economist those are puzzling, because these are the people who have complete coverage, or more or less complete coverage. For Medicare+Choice, I have my own suspicion that there's a lot of a case mix effect there. That the beneficiaries who are dying in Medicare+Choice are predominantly cancer, or more likely to be cancer deaths than others, because you don't get -- people who already have substantially crippling congestive heart failure are less likely to enroll in a Medicare+Choice plan and they'll stay in the fee-for-service program.

The short answer is, I thought that a piece of the Medicare+Choice answer was case mix. That the predominant Medicare+Choice decedent. But I have absolutely no evidence to tell you that because I have nothing to look at.

For the Medigap result, it was anybody's guess as to why people with Medigap would be more likely -- I assume it's a sociodemographic thing that I haven't measured. They are wealthier, or they are better off, or they're better situated, or something. Or they're more interested in complete coverage and so that's why they're willing to go into a more comprehensive care at the end of life. Couldn't give you a reasonable response to that.

MR. HACKBARTH: Anyone else?

MS. BURKE: One of the things you didn't talk about in the text and don't refer to in the context of this first analysis is the issue of the structure of the benefit itself and the decision ultimately that has to be made by the patient with respect to the choice of palliative care as compared to curative care, and

whether the way we have structured it and the fact that people have to make a choice has had a major influence on a decision to use hospice. That you essentially acknowledge where you are in your treatment and essentially give up traditional treatment. And whether that timeframe, the prediction of six months left to live, whether those things have had an unreasonable influence, or an inappropriate one on the decision to seek hospice.

The shortening of the period of time, how late in the process people go in order to choose to go into hospice, how much of that is given by the way we've structured the benefit? I didn't know whether ultimately -- I mean, you touch on it in the outline at the outset -- whether ultimately you expect to look at that issue at all.

DR. HOGAN: No, you have my ultimate product right here. Now it's your report to do with as you see fit. Certainly the six-month prognosis, as has been pointed out by many people, is the reason that you don't get many --

MS. BURKE: You see that in one of your charts where that's indicated as a significant indicator.

DR. HOGAN: You'll see that in the next presentation discussed pretty explicitly, and I think everybody in the hospice industry points to that and says, this is a problem. So yes, there is something to be said there, but I was not the person to say that.

DR. STOWERS: Chris, I just had a quick question. On this counties with no evidence of hospice, how did you break that down, and how many total states have at least some counties without -- because I know of a couple that aren't on here that --

DR. HOGAN: There's a state-level chart in the report showing the percent of rural decedents in counties with no evidence of hospice. So you just have a state-level number, and most of those round down to zero. So if there were a small county in a large state it would show up as zero on the chart.

MR. HACKBARTH: Thank you, Chris.

DR. KAPLAN: Jay Mahoney has been involved with hospice since 1982. He was the CEO of the National Hospice Organization for 15 years, that now is known as the National Hospice and Palliative Care Organization. And for the last four years he's been consulting with hospice organizations.

MR. MAHONEY: Good morning. While Sally is working at putting the slides up I think we'll just offer a few quick introductory remarks regarding the interview process with our key informants.

Our interview instrument asked the key informants to tell us what they felt were the most important barriers to access to the Medicare hospice benefit. We did not try to assist their response by providing a list of possible responses to rank order, nor did we ask them if any specific issue was a barrier to access. Obviously if we had asked for a rank ordering or a

yes/no response to a prescribed list of barriers we may have received a different response.

For purposes of this interim draft report I have collapsed similar responses into categories of response. You should also know that not every informant responded to every question, while others had something to say about everything.

As this slide suggests, the overwhelming response to our question about access was that indeed eligible beneficiaries do experience difficulty in accessing the Medicare hospice benefit. Our key informants responses suggest that issues of access can be separated into those barriers that prevent patients ever being referred to a hospice from those barriers that simply result in late referrals. There are similarities in the barriers, but they are not identical, and similar barriers may influence the two categories of access to different degrees.

This slide generally represents what the key informants reported were the most significant barriers to ever being referred to a hospice program. The requirement of a six-month prognosis appears to be the most significant barrier to ever being referred. Doctors do not like to make such prognostic determinations, and the literature would suggest that when they do make such determinations they are more often than not wrong.

Discussions about prognosis are difficult. Doctors are not particularly well-trained for this type of discussion and often times the patient and family do not want to engage in this discussion. Some have suggested that accepting a referral to a hospice program is an admission of hopelessness and impending death.

Another issue of note that was reported to us was the inability for a patient in a skilled nursing bed to access hospice care. The patient often makes this choice for financial considerations, but in doing so the patient may not access hospice care. Some suggested that by making the choice the patient is prevented from receiving optimal end of life care.

Many of our key informants suggested that some hospices contribute to barriers to access, although several informants also noted that such actions by hospices are sometimes a matter of survival rather than choice. Concern about admitting a patient who will ultimately prove too expensive for the hospice to care for is certainly an issue for some hospices, and we will discuss this issue in later slides. Some hospices operate under a very strict interpretation of what constitutes appropriate hospice care, resulting in their limiting their own admissions.

Regulatory concerns were also frequently mentioned. Key informants reported that hospices are concerned about being denied payment or being required to provide burdensome levels of documentation to substantiate an admission. As many hospices lack the resources to appeal denials or provide additional documentation, hospices simply adopt more rigid admission

criteria.

Patients with non-cancer diagnoses were identified as the group that faces the most difficulty being referred to a hospice program, although the literature suggests that this population is a growing proportion of hospice patients. Certain ethnic and racial minority groups continue to face barriers to hospice care for a variety of reasons, none of which appear to be a result of specific requirements of the benefit.

However, in answer to one of the questions from the previous presentation, the data that we have would suggest that the number of minority groups being served by hospices has grown substantially but probably still is not to where it should be.

Patients in nursing homes face barriers. These barriers are the result of the skilled facility issue we previously discussed, as well as a reluctance on the part of some nursing homes, as well as hospices, to create relationships with each other. The older-old appear to face barriers, which are probably the result of a combination of caregiver issues as well as residency in nursing homes.

This slide talks about the reasons for short lengths of stay. I think it's important to note that the impact of a late referral diminishes the hospice's ability to provide quality care to the patient family. The literature suggests that physicians report an optimum time for hospice involvement to be three months. Additionally, a decrease in length of stay, coupled with an increased intensity of services, increases the per diem cost to the hospice for each patient.

Although as I mentioned there appear to be similarities between the barriers identified to ever being referred to a hospice and those identified as barriers to timely referral, there are important differences. The most significant to timely referrals include the availability of less toxic therapies and the Medicare hospice benefit requirement to forgo curative care.

In recent years, medicine has made available therapeutic agents that allow patients to attempt cure of their disease without the debilitating side effects. While the probability of cure may be no greater than what it was, the choice to try such therapies is not so difficult to make as it may have been at one time. These therapies may also be quite appropriate as palliative interventions. However, in either case, the cost of these therapies which are otherwise generally covered by Medicare can be prohibitively expensive for most hospices to cover under their per diem payment program.

In previous slides you may have noticed that our key informants identified the lack of physician and patient knowledge about hospice care as being important barriers to access. When asked what would improve the consumers' understanding of the Medicare hospice benefit, based on the idea that an informed consumer would be in a better position to ask their physician

about hospice care, many of our informants suggested that the greater effort should be focused on educating the physician.

The question was posed, what uniquely rural issues affect access to hospice care. Our key informants suggested to us that when a hospice in a rural area stopped serving an area, it is unlikely that another hospice will step in to serve those patients, so hospice care simply becomes unavailable. In urban areas, other hospices almost always step in to fill and service gaps.

Our key informants reported that the most significant problem facing hospice serving rural areas is the challenge imposed by the great distances involved in caring for some patients. The challenge of distance directly contributes to the cost of care, as well as indirectly, by requiring the hospice to recruit and retain additional staff.

Another issue was a general lack of services was identified in several different ways as contributing to the challenges facing hospices in rural areas. Such things as lack of wireless availability for pagers as well as cellular phones complicates on-call coverage. A lack of public transportation, other professional services, auditing firms, educational services, even office supply stores, all add to the cost of care in rural areas.

Recruiting and retaining qualified staff is a challenge in many part of the country. However, our key informants reported that this problem is even greater in rural areas where, if qualified staff can be found, they are often willing to commute rather long distances to obtain the higher salaries available in more urban settings rather than accept the lower salaries offered by rural hospices.

The ability to take on the risk of serving potentially costly patients is limited by a small census. Now census size is obviously not an issue of geography, but in rural areas hospice providers generally do not have a choice about their small size. Small hospices in urban areas can grow larger or merge with other programs. These options are seldom available to small, rural programs.

Our key informants had many ideas for improving the Medicare hospice benefit. Some of the options most often mentioned included modifying the six-month prognosis requirement. Our key informants had many suggestions how this might be accomplished, but the idea of determining eligibility based on some type of functional assessment of the patient that may indeed be built around a limited prognosis but that does not specify an exact period of time that a patient has to live was suggested by several.

Other key informants suggested that the benefit should be expanded to include ongoing consultative hospice services, while others suggested the creation of a residential level of hospice care.

Modifying certain payment policies was also suggested, including the adoption of an outlier policy and/or some mechanism to limit the risk to hospices of caring for people receiving costly therapies.

In addition to these suggestions, our key informants identified several other issues including re-basing the hospice rates as areas for additional further study.

That's my presentation. I'll be glad to take any questions that you have.

MR. HACKBARTH: Questions?

I have one, John, about the short lengths of stay. You have the graph, the most important reason for short lengths of stay. Here there's no reference to case mix or any of the factors that Chris identified as correlating with the decline in length of stay. Can you shed any light on why the people you talked to didn't identify those factors?

MR. MAHONEY: I don't know that they were thinking about it in terms of case mix. I think generally speaking -- and this answer is a combination of what we heard from our key informants as well as what's in some of the literature, non-cancer patients have more difficulty ever being referred to the hospice program. But in many cases, those patients with non-cancer diagnoses who are referred to the hospice program actually have longer lengths of stay than you'd find on average.

Cancer patients, on the other hand, generally are referred to hospice programs and don't seem to have a great deal of difficulty in being referred. But there seems to be greater problems in terms of their being referred on a timely basis.

DR. NELSON: John, I'll ask you this question so Sally doesn't have to fuss with it. I assume from the fact that you don't have any bars on your graphs that suggest that capacity is a problem. That is, that patients who are eligible and referred don't have to wait in a queue to obtain hospice services. I'm making an assumption since you didn't include it among the barriers, that indeed, capacity is just fine and that's not a factor. If that's the case, then I'll shut up on this point.

MR. MAHONEY: I think that the question is a good one and you actually shouldn't shut up about this point actually. I think that we're not seeing a lot of that issue surface just yet across the country. I think that where we do have capacity issues, are associated with hospice programs that have no inpatient programs. So where you might find waiting lists is where people want to access an inpatient hospice program and they don't have access to that because the beds are filled and they simply have to wait.

Another area that we're beginning to hear more about, but it's on an anecdotal basis. And again it actually goes to rural issues where hospice programs are simply having so much difficulty recruiting and retaining qualified nurses that in those cases

they're simply having to stop taking patients for a period of time because they can't find anybody else to do the work. But we don't have any real data on that that I could say is national data.

MR. HACKBARTH: Any others?

Thank you, John.

DR. KAPLAN: This report is due in June 2002. We believe that we have a story to tell about beneficiaries' access to hospice. By synthesizing the information from these two studies and other sources that are available, other studies that have been done, we do not anticipate any additional work on access at this time, unless of course the Commission directs us otherwise. We will begin looking at suggested policy options from a number of sources, including these studies. We'll evaluate the advantages and disadvantages of the options and include them in a discussion in the report. You'll see the synthesis and the discussion of policy options in March.

One problem we face in discussing payment policy options is that the hospice cost report data will not be available for use in the June report, at least as far as CMS has been able to let us know at this time. As a result, the solution part of the report will be conceptual.

We'd like your comments, questions, directions.

MR. HACKBARTH: Any comments or requests?

DR. NEWHOUSE: I'll hold on the discussion of payment policy options until we get there. In terms of the urban-rural differences that have been discussed, one of my concerns is that informants -- maybe I should have directed this to John -- I wonder whether they really know urban and rural costs. CMS doesn't know, for example, travel costs separately. You have to see some data that compared them. Even then you'd have to wonder, given the data Chris showed on the heterogeneity of the rural, what really you had. So I'm a little skeptical that somebody can just report about urban and rural and that we should lay much weight on that.

Second, I would say that lower nominal wages in rural areas are presumably to some degree offset by lower cost of living, but that's hard to quantify. Those are really just caveats on trying to interpret urban-rural numbers.

MR. HACKBARTH: Any reaction to that, Sally or Kevin?

DR. KAPLAN: I agree with you. I think that not having the cost report data, and as we found with the home health study in the rural report, it's very difficult to find travel costs on the cost report. What CMS basically concluded about home health agencies, which have a similar problem in rural areas of travel costs, is that the rural travel costs were basically offset by urban costs such as a monitor or a person to ensure the safety of the home health professional, would offset the rural travel costs.

DR. STOWERS: Maybe someone could help me. We're talking about the cost, but is there a payment difference? Is there a geographic adjustment, and how much is that? What would be the differential between an urban and --

DR. KAPLAN: There is a wage index, and it's not clear to me -- I can't remember at the moment how much of the payment is subject to the wage index. But there is a wage index.

DR. STOWERS: I was just curious what the dollar difference in a visit would be, or an episode.

DR. KAPLAN: They get paid by day. In other words, each day that a person is enrolled in hospice, the hospice is paid a daily rate based on the type of care they receive during that day. For instance, if they received routine home care then they're paid for routine home care for that day. Then that rate has a labor-related portion that is subject to the wage index. Right at the moment I cannot pull the table up in my mind that has what the labor-related portion on the routine home care would be.

DR. STOWERS: My question is, the cost very well may be different, and the payment may be different, but I wonder how the two are matching, or whether we're actually reflecting the real cost compared to the payment. I think it's something we need to look at.

DR. KAPLAN: It is something we need to look at. But I think the point is that hospices have not submitted cost reports until very recently, and the cost reports were theoretically going to be available in 2001. But as you know, all cost reports have been delayed for the last cycle for 2000. So it's going to be very difficult for us, without cost reports available, to give you any idea about differences between costs and payments, differences between rural and urban in cost. We can give you an idea of differences in payment.

There's also the issue of the fact that these rates were established based on a demonstration in the early '80s, and although they've been updated those rates were really structured very differently from the way the hospice benefit is now. But there's no way to really look at anything to see whether the rates are appropriate or not without the cost reports.

DR. NEWHOUSE: That's the larger issue, Ray. This thing for urban-rural is just the entire base for the rate, both urban and rural.

DR. STOWERS: Exactly. I agree. I know, for example, in the county that I practiced in, when we finally did get hospice that we were actually paying more hourly for the nurse's care than what they were paying in the larger cities just to get the nurses out into that area. So I think sometimes the cost of living or wage index is kind of skewed that way when you really have to go to these remote areas.

DR. BRAUN: Just a point of information. If a Medicare beneficiary in a nursing home who is on Medicaid in a nursing

home, if they go into hospice what happens with the benefits?

DR. KAPLAN: If a person is eligible for Medicaid, Medicaid pays the hospice and the hospice pays the nursing home, I think it's 95 percent of the daily rate. Then also the hospice receives the hospice rate for the hospice care.

DR. BRAUN: It still seems to be some duplication.

DR. KAPLAN: When Chris referred to the OIG, that was part of the OIG's point is that there could be some overlap, and it appeared that they found that some of the hospices were really using the nursing home personnel to provide care and were not providing all that much additional care.

MS. RAPHAEL: Sally, I'm assuming that because of the lack of cost report you couldn't tell us, as we've seen in other sectors, what the financial performance looks like for hospices?

DR. KAPLAN: You're right, we cannot.

DR. NEWHOUSE: The freestandings would have to break even to stay around anyway, so to some degree the costs are just going to reflect what we pay. So then there's a judgment about, what are we buying for what we're paying, that's going to be hard to make.

MS. RAPHAEL: I think a lot of freestanding that I know about do considerable fund-raising to try to make up the deficits. I don't know how prevalent that is.

DR. KAPLAN: I think it's pretty prevalent. Of course, they're required to get in-kind contributions through volunteers. So not only are they fund-raising to raise funds, but they can use the volunteers. But then there is also a restriction that a certain proportion of their services, a very large proportion of the services have to be provided by their own employees, which appears to be to keep contract employees from being used extensively, except in peak periods or in emergencies.

Any other questions or directions?

So the timing of this report, with Congress asking for it in June 2002, if the cost reports had come in when they were expected to come in and basically had been edited and CMS was confident about them, we could have given them a whole lot more information. But as a result of the cost report problem, much of our discussion of the solutions to the problems in access are going to be conceptual.

But that doesn't mean that we can't make recommendations such as, when the cost reports are available, we direct you to look at them and consider re-basing, or something like that. But we're not going to be able to come up with a very -- as firm a statement as we could with the data.

DR. REISCHAUER: Your description is that Congress thought the cost reports would be available when it set the timetable for our report and we can't give them really what they want because the cost data isn't available. Does it make sense to do this that way, as opposed to go to Congress and ask -- is this in legislation so we couldn't do a three-page letter saying, we're

fulfilling to the extent possible the requirement, realizing that we really can't fulfill it until the cost reports are available, and we'll report back with a more substantial --

DR. ROSS: I think we give what we can by the statutory deadline. It doesn't end the Commission's interest in this or future work. The analog here might be the GME teaching hospital study where we provided a very short, conceptual report to meet the statutory deadline and did a lot of follow-up work.

DR. REISCHAUER: Because I sense there's a lot of interest on the Commission on doing this right.

MR. MULLER: Is there considerable or any kind of cross-ownership between home care and hospice.

DR. KAPLAN: There is some, yes. But I don't want to say it's considerable. It's actually less than I thought it would be. One of the confusing factors is that you have hospital-based hospices. Hospitals can have a hospice, and they can have a home health agency, so they're related. But you wouldn't really identify that because it would be a hospital-based hospice.

MR. MULLER: But independent of an institution like that --

DR. KAPLAN: There are a number of freestanding, and there are more freestanding hospices now than at the beginning of the '90s.

DR. NEWHOUSE: But I thought 90 percent of the care was delivered in the home.

DR. KAPLAN: That's correct.

MR. MULLER: If there's a payment advantage to going one direction or the other, you reorganize yourself.

DR. REISCHAUER: Are there for-profit entities?

DR. KAPLAN: Yes, there are for-profit hospices, yes.

DR. REISCHAUER: When we're talking about the adequacy of the payment, it might be interesting just to look at the trends in the growth of numbers and capacity in the for-profit sector. It should tell you something about the adequacy of payments.

DR. KAPLAN: We can do that.

DR. REISCHAUER: And also about their locations, too.

DR. KAPLAN: Exit and entry, if we consider that exit and entry is an indicator of payment adequacy, if you'll excuse my using adequacy without defining it, then we would say that the hospice payments must be decent or appropriate because we've seen a lot of entry.

DR. NEWHOUSE: But there's a problem, because they may be adequate to make a profit provided you get the right case mix, and you may decide there's certain classes of patients that you're not going to take because the rate doesn't suffice.

DR. KAPLAN: Right.

DR. REISCHAUER: But at the same time, Chris' numbers, if they hold up past 1998 show a substantial growth overall.

DR. NEWHOUSE: There's no question in my mind that the rate is quite adequate for many patients.

DR. ROWE: I think this conversation reflects the possibility that individual hospices, be they for-profit or not-for-profit, may have more than one payer. If you just looked at whether nursing homes were open and said well, they're still open, so the Medicaid payment rate must be adequate. But then you go to the nursing home and you see they have a certain proportion of private pay clients and they really require those in order to get by. If it was just the Medicaid patients, many of the nursing homes might not be able to get by.

We shouldn't assume that whether a hospice is making it or not, or there's entry or there isn't, is a direct reflection of the Medicare payment rates until we look at what proportion of the patients in these hospices are from private pay or commercial payers or whatever.

So if you're going to look at the for-profits, you might look at the proportion that are Medicare beneficiaries in addition to whether there's entry or exit.

DR. KAPLAN: For which we need the cost reports.

DR. NEWHOUSE: But we know that about roughly three-quarters of the decedents of all types are Medicare.

DR. ROWE: One-quarter private pay would make a huge difference.

DR. NEWHOUSE: In our interviews with the hospice industry, the industry on a whole seemed to like Medicare, to deal with Medicare because of the flexibility within the all-inclusive rate that Medicare afforded.

DR. STOWERS: I was just going to say that while we're looking back to the volunteer versus profit or hospital-based, I know in our region what hospice care there is, and there are several gaps in several counties, that it's all volunteer organization driven and there's fund-raisers and all sorts of things. They by, are by no means, being supported by their Medicare income.

So I think whether it's urban versus -- you know, I think some of these communities have got together to bring in other resources to make this work. But they're sure not making it on Medicare income alone, I know that for sure.

MS. BURKE: Sally, I wonder as you began to think about the report and reflecting on that charge from Congress, in addition to the payment rate issues that we've spent a fair amount of time talking about, there are a series of issues about internal limits, use of inpatient days, and a variety of other things that were part of the initial benefit. And I wondered to what extent you anticipate looking at those issues, and to the extent that they limit people's use or have an influence on people's use of the benefit, as well?

DR. KAPLAN: I think we are going to look at some of the issues. In fact, I know we're going to look at some of the issues that have been named by the key informants as potential

access problems or barriers to access, and try to come up with a discrete number of solutions that might solve those. And then discuss them in terms of the pros and cons of doing that. Particularly I know we're going to look at the six month prognosis issue.

Some of the other issues really get into more -- we had planned, when we looked at this, because of the way the mandate really is stated, is to look at it within the context of the current benefit. So we really had not planned to get into the larger aspect of "end of life" care. We really were going to look strictly at hospice.

But as Dr. Rowe said, it doesn't restrict the Commission from looking at end of life. It's just that in this report we're going to do it in the context of the current benefit.

MS. BURKE: And it's in that context that I asked the question. There were, at the time we created this benefit, a series of decisions made because of concerns, both in the construction of the demonstration as well as in the final benefit, concerns around use -- because we didn't know enough at that point in time. Concerns about the mixture of services. The limit on the inpatient days was designed for that purpose, so that you essentially didn't try and go around it.

But there are now issues around the nature of treatment that have changed substantially since the benefit was originally enacted. And things that might have been viewed as curative at that time are really now palliative and are not really curative. Issues around certain chemotherapeutic agents.

And so as we look at the issues of payment, I don't want us to lose sight of the fact that in the current construction of the benefit there are a series of decisions that were made inherent to the benefit that may warrant relooking at now because of what we know in our experience with the benefit.

DR. KAPLAN: I think that definitely we'll be getting into the issue of the --

MS. BURKE: Pass-through issues?

DR. KAPLAN: Really, the fact that you have chemotherapies that are less debilitating now that are available. And some of those have been approved by the FDA as being appropriate for palliative. Not all of them have been approved as being appropriate for palliative. So I think we can discuss that issue, as well.

MS. BURKE: Thanks.

MS. RAPHAEL: I agree with Sheila that I think one of the major issues here is [inaudible] and trying to put a treatment into one of those boxes, as well as just dealing with more chronic illnesses where you progressively deteriorate and it's hard to demarcate when they're terminal.

But also another factor that I think is important to consider, are some of the regulatory issues that have really

driven the costs up. And I think they were well-intentioned but have not necessarily been constructive. For example, this issue of not contracting out. I think that it had a very good purpose. But for example, you can contract out for infusion therapies which you would want to do from a quality standpoint because you want a few specialists who really do high volumes. But you have to have one or two people do very few cases and it's just not cost effective.

There's also a requirement that every time you make a change in treatment the whole interdisciplinary group has to approve that. And I think it really tried to promote multidisciplinary care. But it means if you change a medication you have to reconvene your group and really review and approve that.

There are just a number of things like that that I think had a very good public purpose initially but, in effect, are really raising costs.

MR. HACKBARTH: Anyone else? Kevin?

DR. HAYES: We would like to talk to Carol further if she's got other ideas along that line. That sounded like a very fruitful way to proceed, to pursue some of those things.

MR. HACKBARTH: Thank you.